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MassCARE NEWS

Vol.1 No. 1 July 1992

Dear Parents:

Welcome to MassCARE's first newsletter!! It is an exciting moment because this newsletter is just for us--parents of children in Massachusetts who are infected or affected by HIV. Some of us are HIV+ ourselves, others are HIV-. Some of us are birth parents, others are foster, adoptive, or extended family members, but our children link us together in the most basic way.

Living with HIV is often isolating and scary. So many times I have wished for the opportunity to feel more connected with other parents of HIV+ kids. Parents whom I have talked with have expressed this wish to me too, so I know that I'm not alone. I really feel that the MassCARE program can help fill that need. Together, we will find ways to learn more about our child's care and plan ways we can talk together and support one another.

This newsletter will be a primary source of information for us. Right now, about 700 families will have access to it through clinics, hospitals, and at agencies that serve families living with HIV. I know that disclosure is an issue for many of us, so, don't worry, nothing will be sent to our homes without permission, nor will we use the words HIV or AIDS in the title. NO names will be used in articles unless we get permission.

Each issue will provide us with information on medical and emotional issues that families living with HIV confront on a daily basis. It will also inform us of upcoming events, groups we can join, and other helpful resources. Best of all, we want to include as many articles written by parents. Remember, this is a newsletter for us, not medical staff or social workers.

Other important resources for parents that MassCARE hopes to establish include: opportunites for us to participate in local and national conferences, to be a part of a phone support network (see article on page three), to attend weekend retreats, to participate in MassCARE projects through your child's health clinic, and to serve on MassCARE and other relevant committees. In some instances, such as committee work, parents will be given a stipend for their involvement. In other instances, we will cover expenses, travel, and childcare.

Most important, in order to make MassCARE a success, we need **YOUR** input and help. In addition to myself, we already have a number of other parents who wish to be active in MassCARE, and we invite--urge--other parents to join us. **Children do not have to get their care at a MassCARE site in order for parents to be part of our project**. If you have questions, comments, or ideas, please contact either Brunilda Torres, MassCARE director, or myself, Katie Bond, at MassCARE's phone number and address listed on page six. Or, if you prefer, you can contact the MassCARE coordinator at your child's clinic or hospital (that list is on page five) or your social worker. They can give you information and let you know some ways that you can become involved in MassCARE at your local clinic or hospital.

I wish you well,

Katie Bond

Katie Bond
MassCARE, parent consultant

BRUNILDA TORRES' WELCOME

Welcome to MassCARE! Our name is short for **Mass**achusetts **C**ommunity **A**IDS **R**esource **E**nhancement, a program of the Department of Public Health and funded by the Maternal and Child Health Bureau of the Department of Health and Human Services [federal government].

Through MassCARE, five community based pediatric HIV clinics have joined efforts with four pediatric HIV specialty care centers in the state. A team of medical personnel from the community health center and specialty care center provide follow up to children who are at risk for HIV or who have the virus in the following communities: Boston City Hospital sees children at Goddard Medical Associates in Brockton; Children's Hospital travels to Greater New Bedford Health Center; University of Massachusetts Medical Center travels to Lowell Community Health Center and Greater Lawrence Health Center; and Baystate Medical Center sees children at Holyoke Pediatric Associates. By providing care closer to home, the program lessens the need for families to travel long distances to obtain medical care for their children. A MassCARE coordinator at each site links families up with local support services. Please note that a child **does not** have to be a patient at a MassCARE site for the family to receive help from the coordinator or to participate in MassCARE.

One of the primary goals of the project is to find ways for parents of HIV infected and affected children to develop support systems. Although a wide range of services for people with HIV/AIDS has grown up over the years, these services do not always address the complex issues that come with parenting children who are HIV+ or parenting as a PWA [person with AIDS]. We hope, with your help, to find ways to fill some of that need.

A parent consultant is on staff to assist with the creation of parent support activities. This newsletter is the initial product of her efforts. It is dedicated totally to you as parents and to your concerns. It is a place for you to find support, to communicate, and to become better informed. The newsletter, along with other parent support projects, will be formats for you to identify your needs, develop your ideas, and to create opportunites to use your skills.

It is my dream that you as parents seize this opportunity to work in a cooperative and collective way to ensure that programs reflect your needs as well as those of your children.

Brunilda Torres is the director of MassCARE

HELP ! ! !
Our newsletter needs a NAME.
Any ideas ? ? ?
We also need to translate it into Spanish. Who can help?

DON'T BE SHY !
Send us your ideas, letters stories, and kids' drawings.
WE WANT IT ALL !

MassCARE NEWS Staff::
Editor: . . . . . .Katie Bond
Production . . . . . .Dennis Sterzin
MassCARE Director . . . . . .Brunilda Torres

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PHONE SUPPORT NETWORK

Chances are that you will answer yes to at least one of the following questions:

- When you found out that you or your child had HIV did you want to speak to another HIV + person?
- Have you ever wanted to talk to another foster parent about the DSS system?
- Have you ever had to make a decision about whether to put your child on a drug study and wanted to know another parent's experience with the drug?
- Have you ever just needed to hear a supportive voice of someone who is also living with HIV?

There are times where only another HIV+ person or another parent of an HIV+ child can understand what we go through in our day to day lives. As much as people whose lives are not intimately touched by HIV try to help, it's difficult sometimes for both them and us. Because of that, we at MassCARE have come up with an idea for a **Phone Support Network.** We feel that the network will make it easier for parents to be supports for one another. We have some ideas about how the network might work, but--as always--we need your input on the plan.

As we see it, MassCARE will gather a list of names of parents across the state who are interested in being phone resources for other parents. When a parent contacts MassCARE with a particular problem or concern that another parent might be able to address, we will arrange for the two persons to be in touch by phone. **As a parent resource, you won't have to share your phone number with anyone, unless you want to.** Instead, you can place the phone call to the other parent. **Nor will you have to give your name or address.** You can talk annonymously or use just first names.

To help us learn how to be effective phone resources, MassCARE is in the process of setting up training sessions for interested parents. It's important to make sure we know what we can and can't do for other parents. In addition, there will be ongoing forms of support for parents who are trained as resources.

MassCARE will reimburse for all phone calls and travel to trainings. There will also be on-site childcare and/or money for home childcare during the trainings.

If you are interested in being a phone resource, please contact Brunilda or Katie or the MassCARE coordinator at your child's clinic.

Boston Pediatric AIDS Project

We want to let parents know about Boston's Pediatric AIDS Project. We hope that you will contact them if you feel they may be able to provide you with information or support.

The Pediatric AIDS Project is a network of community health centers, hospitals, and social service agencies serving Boston area families who are at risk or infected with HIV. Housed at Dimock Community Health Center, this federally funded project provides confidential education, counseling and testing, outreach, support services, medical care and advocacy to any family affected by HIV/AIDS, regardless of ability to pay.

In addition, they have recently set up a Babysitting/Respite Care Fund. Stipends of $15 per day for one child or $25 per day for two or more children are now available. You can offer a stipend to a friend, relative, or neighbor when they do childcare for you. There is no mention of HIV/AIDS on the check that your sitter receives and no limit to how many times you can use these funds.

Submitted by Ruthie Liberman, Director of Boston Pediatric AIDS Project. Call her at (617) 442-6758 for more information about the project.

Family Network Weekend: "a time for caring, love, and laughter"

MassCARE and Boston Pediatric AIDS Project sponsored nine parents to attend the Association for the Care of Children's Health's [ACCH] Family Network meeting, March 6-8,1992.

If you are unfamiliar with ACCH, it's a wonderful resource for families who are living with HIV. ACCH brings together professionals and families in partnerships to improve health care and support services for children and families.

ACCH has established two "networks," the *Parent Network* and the *Family Network*, both of which parents with children who have HIV can join. The Parent Network began in 1982 and consists of about 1000 parents of children with all kinds of chronic illnesses and disabilities. Members meet once a year. The Family Network is *only* for families (birth, foster, adoptive, extended) who are caring for children with HIV disease. There are 200 families who have joined the network from all over the U.S. and Canada; they meet about three times a year. There is also a newsletter that Family Network members can receive for free, if they want.

The most recent Family Network gathering in March was held in Linthicum Heights, Maryland. All meals and snacks were provided (the food got raves from our parents), and parents slept two to a room. There was also a swimming and weight room. The weekend is meant as a time for parents to spend with each other, so it is best if children stay at home. No childcare was provided.

There were many activites, including workshops such as "how to talk to and evaluate the media," "how to deal with rejection," and a "fathers only" workshop. There was also time to learn what other parents are doing around HIV awareness, time to add panels to a quilt, and even a chance to make a video of yourself for your family. Parents choose what they wanted to participate in--you don't have to do anything, if you don't want.

Parents from Massachusetts were very enthusiastic about the experience. They agreed that the most important part was being able to share feelings and to spend time with other families. Debbie Hill, who parents her niece, Tiffany, age two, said, "I found a lot of caring, love, and people who listen. A lot of laughter, too." One mother of a young child said that she "wanted to cry with everybody" and give them all hugs when she heard other parent's stories. Another mom urged parents to "go, and you'll learn that you're not alone!"

If you would like to get more information about ACCH, call them at (301) 654-6549, and ask for Valencia Clarke. They will accept collect calls from parents. The address is: 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814.

New Bedford Health Center

In each issue, we hope to profile one of the MassCARE sites.This month we focus on New Bedford's program.

The Greater New Bedford Community Health Center (GNBCHC) began its pediatric infectious disease clinic in conjunction with Children's Hospital AIDS program (CHAP) in January 1992. The clinic, held on the 3rd Thursday of each month, offers children in the Greater New Bedford area the opportunity to see Dr. Ken McIntosh and the staff from Children's Hospital without going to Boston. Louise Norko, a pediatric nurse practitioner, is the GNBCHC community coordinator/case manager for the children and their families who attend the infectious disease clinic. Children who are at risk for HIV or who have HIV infection can be referred to the clinic. Louise and CHAP will work with the child's regular doctor to provide the care and treatment needed.

In addition to medical care, GNBCHC staff counsels families around HIV education and testing concerns and helps them find other supports and services that they may need. GNBCHC social worker Carol Reeve works with families to help resolve these issues. The clinic also makes referrals to other community support services when needed.

Submitted by Louise Norko, GNBCHC MassCARE coordinator.

MassCARE COORDINATORS

The left column in this list gives the contact information for each community health center in the MassCARE program. The right column gives a contact person at the hospital that is linked to the health center.

1) BROCKTON Rosie Vasquez, coordinator: 508-586-3600 ex. 2778 Goddard Medical Associates 1 Pearl Street Brockton, MA 02401	**BOSTON CITY HOSPITAL** Tina Schwartz, RN 617-534-5806 Dept. of Infectious Diseases 774 Albany St., 5th floor Boston, MA 02118
2) HOLYOKE Steve Torres, RN, coordinator 413-784-5014 Children seen at Holyoke Pediatric Associates but contact Steve Torres at Baystate Medical Center	**BAYSTATE MEDICAL CTR.** Steve, Torres, RN Marypat Toye 413-784-5014 Springfield Hospital Unit Pediatric 3rd Floor Springfield, MA 01119
3) LAWRENCE Terri Tellez, coordinator 508-685-1770 Greater Lawrence Family Health Center 150 Parker Street Lawrence, MA 01841	**U. MASS MEDICAL CTR.** Amy Sharples, RN 508-856-0011 Dept. of Pediatrics 55 Lake Avenue Worcester, MA 01655
4) LOWELL Millie Diaz, coordinator 508-937-6100 Lowell Community Health Center 597 Merrimack Street Lowell, MA 01852	**U. MASS MEDICAL CTR.** Amy Sharples, RN 508-856-0011 Dept. of Pediatrics 55 Lake Avenue Worcester, MA 01655
5) NEW BEDFORD Louise Norko, RN, coordinator 508-992-6553 Greater New Bedford Community Health Center 1204 Purchase Street New Bedford, MA 02740	**CHILDREN'S HOSPITAL** Nancy Karthas, RN 617-735-8202 300 Longwood Avenue Carnegie 3 Boston, MA 02115

WOULD YOU LIKE THE NEWSLETTER BY MAIL? IT'S FREE!!!

Yes, I wish to receive MassCARE News by mail.

I want to help with MassCARE. Please call me.

NAME _____

ADDRESS_____

CITY _____**STATE** _____**ZIP**_____

PHONE _____

Please return this form to: Katie Bond, MassCARE, Dept. of Public Health, Division of Children with Special Health Care Needs, 150 Tremont St., Boston, MA 02111

How To Reach MassCARE

Brunilda Torres, MassCARE director, and Katie Bond, parent consultant, can be reached at:

(617) 727-6941.
Department of Public Health,
Division of Children With Special Health Care Needs,
150 Tremont St., Boston, MA 02111.

You can also get information through the MassCARE coordinator at your child's clinic.

Other Useful Numbers

Dept. of Public Health HIV Info:

- **(617) 727-6971. Open 24 hours.**
  A voice mail line; it gives info. on anonymous HIV test sites across the state.
- **1-800-243-2437. Mon-Fri 9-5**
  Offers statewide info. on HIV services and phone referrals. It is particularly useful for newly diagnosed persons. It will not be answered if DPH staff are away from their desks. If you don't get through, keep trying!
- **1-800-882-1435. Mon-Fri 9-5**
  Child SSI/Public Benefits line. It offers info. and technical assistance on SSI for disabled children, includiing Medicaid issues.

AIDS Action Committee Hotline:

- **1-800-235-2331 or (617) 536-7733 (ex.250 for bilingual access) Mon-Fri 9-9, Sat 10-2**
  Hotline offers HIV testing info., phone support and agency referrals. They will accept collect calls from people in prison or in crisis.

Federation for Children With Special Needs:

- **1-800-331-0688**
  (617) 482-2915 Voice TDD
  Mon-Fri 9-5
  Provides referrals for parents, info. on special education, and legal rights training.

THE MassCARE COORDINATING COMMITTEE meets once a month at U. Mass Medical Center in Worcester to talk about how the project is going at each health center. We need MORE PARENTS to attend the meetings and share their thoughts. You will be paid a stipend for time and travel. Let us know if you are interested !

MASS. HS30.33:1/2

MassCARE NEWS

GOVERNMENT DOCUMENTS COLLECTION

Vol.1 No.2 December 1992

NOV 1 1993
University of Massachusetts Depository Copy

The Rights of Students With AIDS or HIV Infection

If your child has AIDS or is infected with HIV, your family and your child have certain rights under the law. The Massachusetts Department of Education and Massachusetts Department of Public Health have a written policy that informs schools of how they should act in order to protect those rights. The following is a summary of that policy: For more information, please call Kevin Cranston at the Department of Education AIDS/HIV Program at (617) 770-7477.

1. **Every school-age child has the right to a public education.**

   Your child, whether sick or not, has the same right to go to school, attend classes anc participate in school activities as any other student. Some children with AIDS or HIV infection have special needs. Your child has the right to a public education that deals with these special needs.

2. **Your child and your family have the right to keep their medical condition a private matter.**

   Since HIV cannot be caught by everyday contact, you are not required to tell anyone at the school if your child has AIDS or HIV infection. You may, however, choose to tell certain people at the school so that they may offer better care for your child. For example, you might want the school nurse to know about your child's health, because your child may take medication or need other special care. Or you might want to tell your child's teacher. It is your decision who to tell and when.

3. **If you tell someone at the school that your child has AIDS or HIV infection, they should not tell other people without your permission.**

   There is a law that makes it illegal for a doctor or nurse to talk about your child's HIV infection without your permission. If another person at school tells people about your child's condition without your permission, you have the right to sue them for violating your child's privacy.

4. **You may give people at school permission to tell certain people that your child has AIDS or HIV infection by saying so in writing.**

   You can give your permission in writing to make clear who you wish to know about your child's health. It is in the school's interest to have a form you sign telling them exactly who these people are. They may provide the form to sign, or you may want to write your own. People who work at the Department of Education and the Department of Public Health, Division of Children With Special Health Care Needs, can help you with this.

!! SAVE THE DATE !!

MassCARE retreat for parents of HIV infected children.
March 5-7, 1993
at Craigville Conference Center on Cape Cod.

There will be workshops, time to talk, rest, and have fun.
Space limited to 30.
We need more parents to help plan it !!
Call us at (617) 727-6941

Dear Parents:

Our second newsletter covers a wide variety of topics--from the rights of students with HIV infection to an oppoprtunity to relax at a Maine inn.

As parents, we struggle with whether to disclose our child's illness and what the reaction will be if we do. To help us with that decision, this issue informs us of our childrens' legal rights in school settings. We have included the Department of Education policy on children with HIV infection and new day care regulations for children with disabilities, developed by the Office for Children. There is also an article on MASSTART, a program that helps parents work with school personnel around their child's illness.

MassCARE interviewed two mothers who have had widely different experiences with their school systems. Susan (not her real name) feels that her North Shore community makes it almost impossible for HIV positive kids to attend classes, and she fears discrimination if she discloses. Kathy Gomes, guardian of an eight year old boy, told his New Bedford school. He was immediately accepted and treated the same as his classmates.

One way that we can find support in our decisions around disclosure and other issues is to talk with each other. So it is appropriate that Chuck McCorkle, of DPH's AIDS Bureau, has written an article on the importance of peer support. Kelo Ammons-Blenman, a woman living with AIDS, has written a wonderful companion piece. It is eloquent in its plea for peer support.

On a lighter note, "Moe Scott", lets us know of time spent at a Maine inn that opens its doors to HIIV positive persons and their caregivers.

I am grateful that parents have come forward and shared their experiences with the rest of us. In doing so, we build bridges to each other.

I wish you well.

Katie Bond

Katie Bond

New Day Care Regulations

1. Day care centers must accept applications from all children with disabilities, regardless of the type or severity of disability.

2. The parents and center must determine together if any special changes are needed for a child with a disability to participate in the day care program. These agreed upon changes must be in writing.

3. Children with disabilities cannot be excluded from a day care center simply because they are not toilet trained.

4. The center must identify a teacher who will serve as the "Center Liason" for each child with a disability.

5. The day care center must provide parents of children with disabilities with written progress reports every three months.

6. All new day care centers and all existing centers that move to new space must be fully accesible to people with disabilities as of September 8, 1992.

7. Day care centers must insure that 25% of their staff training is about children with disabilities.

MassCARE NEWS Staff:
Editor: . . . . . Katie Bond
MassCARE Director . . . . . Brunilda Torres

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AIDS and the School System: Two Views

Interview With "Susan"

MassCARE: When did you first begin to have fears about your local school system?

Susan: Last year, my older daughter [who is HIV negative] had an HIV awareness class in science. The teacher taught wrong information, such as "we don't really know how the disease is transmited." The kids in the class were frightened, and the way my friends and neighbors believed him made me realize my family will have a hard time if we disclose our illness.

MassCARE: What happened after that?

Susan: A friend of mine, who is on the Board of Education, told me, without knowing that my child has HIV, that she wanted to keep kids with AIDS out of the schools because "you can't be too careful." Then I saw the school policy. It states that no medicine can be left at school during the day, and that it can *only* be given by parents during school hours. Teachers and nurses can't give it to the child, nor can the student leave it in her locker and take it herself. I feel this policy is designed specifically to exclude kids with HIV because they tend to take a lot of medicine.

MassCARE: Where is she in school now, and what will you do in the future?

Susan: Right now she is in a private kindergarten that is only half a day, and she gets her medicine at home. I'm thinking about sending her to Catholic school because I don't think some of them have as strict a medication policy. By then she will be old enough to take her own medicine. If I have to explain why she needs it, I will lie.

MassCARE: How do you get her school to inform you of outbreaks of chicken pox [which can be more serious in HIV positive children than in healthy ones] and other illnesses without making them suspicious?

Susan: I tell them that she hasn't had chicken pox, even though that's not true. I also tell the teachers that we have someone in our house with cancer, and we need to know if my daughter is exposed to any disease. When I pick my daughter up, I check the kids over to see if anyone has an obvious rash or cold.

MassCARE: What advice would you give parents?

Susan: Tell only on a "need to know" basis. Think very carefully before you tell in order to protect your child.

Interview With Kathy Gomes

MassCARE: When did you first tell the school system of your son's HIV disease?

Kathy: When he was in kindergarten [he is now eight], I told his teacher. She adored him and felt really bad but was glad that I brought it to her attention. I told her that I would tell the principal and nurse. Everyone has made us feel comfortable.

MassCARE: Does he get his medication at school?

Kathy: No, he takes it at home. He is in an after school program, and they were willing to give it to him as long as I got the appropriate forms filled out. But I felt uncomfortable, because I did not want to leave it for someone else to do.

MassCARE: Do they inform you when other kids are sick?

Kathy: Yes, they have been on top of it.

MassCARE: What can you say to other families?

Kathy: I would be open, but I also understand, since he is not my biological child, that it may be easier for me to do than for some other parents.

Rest and Relaxation in Lee, Maine

Time to Relax !

Mt. Jefferson Inn, located in the rural town of Lee, Maine, is the perfect place to get some rest and relaxation.

Just a few months ago, Larry Demeron, proprietor, decided to use his inn as a place of respite for people with HIV and AIDS.

My son and I arrived on a cloudy afternoon and were welcomed warmly by Rick, the inn's assistant. After our tour of the facilities, my son, age three, bolted out to the spacious yard and found that climbing a big tree was very muich to his liking.

It was the fourth of July weekend, but, unfortunately, all the festivities were canceled because of the heavy downpour. So the rest of the time we spent watching television and getting needed sleep.

Guest staying at the inn can swim during the summer and cross country or downhill ski during the winter.

"Moe Scott" is a woman who is HIV positive and the parent of an HIV positive son. .

If you have a medical question about HIV or AIDS that you would like answered, let MassCARE know. We will ask a doctor or nurse to respond and print the answer in the next issue of MassCARE News.

Mt. Jefferson Inn

In March of 1992, Larry Demeron. opened the Mt. Jefferson Inn. He had raised his family in the house but, after having worked at Eastern Maine AIDS Network for five years as a "buddy" and volunteer, he decided to turn his home into a bed and breakfast for people with HIV/AIDS and their caregivers.

People are welcome to stay as long as a week, and, as money is tight for many people with HIV/AIDS, he rquests a voluntary donation of cash or of physical labor. Right now the inn is not fully wheelchair accesible, but there is one bedroom on the first floor that guests may use. He provides breakfast, and guests are asked to bring food for lunch and supper (there are also a few restaurants nearby). The house is not geared to families with toddlers, although infants and older children are welcome.

For guests who do not have a car, there are buses to Bangor, Maine. From there. Larry can transport people to the inn, about an hour's drive from Bangor.

The inn will be closed from October 1st 1992 to the end of January 1993 but will be open the rest of the year. For more information, Larry can be reached at: P.O. Box 267, Lee, Maine 04455-0267. (207) 738-5049.

If you want to become involved with issues around pediatric protocols (drug studies), join a community advisory board of the ACTG (AIDS Clinical Trial Group).
Boston--Ruthie Liberman: (617) 442-6764
Rest of Mass.--MassCARE (617 727-6941

Plan Ahead !!

HIV/AIDS and Disability Network
will hold four day long programs, beginning February 1993, in Springfield, Worcester, Lawrence and New Bedford.
Presentations on disability issues for people with HIV disease.
Panel on women and families.
Contact Jo Bower: (617) 727-6374

The Benefits of Peer Support When Facing HIV Disease

Learning that you or your child is HIV positive can be initially overwhelming. You may experience many feelings at once, including a sense of isolation. The first step in breaking that isolation is to remember that *you are not alone*. Perhaps as many as 50,000 people in Massachusetts are living with HIV (at least 109 are children, under age 12, with AIDS). You may also feel that your family's life is in the hands of medical personnel and insurance companies. This sense of loss and feeling a lack of control may cause additional anxiety. Remember, however, as an HIV positive person or parent of an HIV positive child, you are on your way to becoming an expert in the field, and, with help, *you will become your own and your child's best advocate*.

How, when feeling overwhelmed, do you begin to reach out and start to take some control over decisions regarding your family's health? Talking with others who are facing the same difficulties and who are asking the same questions is a good place to start. That's what peer support is all about. As well meaning as relatives, friends, and health care providers may be, they do not always understand what it is like to be living with HIV or to have AIDS. This newsletter is the beginning of a network that may help you connect with other parents across the state who, like you, know first hand what it means to be living with the disease. When you hear their stories and talk with them you will feel supported in your decisions and be able to begin to break the isolation that you experience. Knowing that you are part of a larger network of families can instill a sense of hope. Through peer support, families can begin to speak with a unified voice; this has the power to affect the quality of care and access to treatment that your family deserves. It is an important step in becoming an equal partner with health care providers and social service agencies.

Peer support, which is working with other families in your same situation, takes work, but it will bring you untold benefits. It offers you the strength of your common experiences, your common struggles, your common sorrows, and your common joys. It makes sense that when traveling a difficult road, we travel it together.

Chuck McCorkle works for Mass. DPH 's AIDS Bureau in HIV Counseling, Testing, and Support Services and provides technical assistance to peer support groups.

One Woman's Wish

There have been so many traumatic episodes since my husband, Rich's, death last September. The pain for me has gotten worse, and it began to manifest into physical pain. In addition to my HIV, I developed asthma, which felt like a tightness in my chest. But as soon as I started dealing with my feelings, my asthma began to leave me. I feel like this stress must leave my being or it can kill me. too.

I'm determined to beat it. Spirituality has helped me live rather than think about dying. My support system has helped me deal with all the rage. You see, I can't do this alone. I need prayers and love. I need to be accepted by my Black community.

I have found that denial keeps covering our eyes, but, with the spread of the virus, sooner or later, everyone will be touched in some way. Education is one answer. Passing out condoms and needles is not the only answer, but it may well save one life.

I have started a support group that is held Sunday afternoons at 4PM at 11 Mary Moore Beatty Circle, #2B, Mattapan. MA 02126. You may also call me at (617) 296-4801.

Kelo Ammons-Blenman is an activist and a woman living with AIDS.

If you have been part of a peer support group, tell us. It will help other parents to know of your experience.

SERVICES

MASSTART

Like many other children with chronic illnesses, HIV positive children often have special treatments or medication needs during the school day. Parents may have concerns around "who to tell" and "what to tell" school personnel, while school systems often lack the technical knowledge or understanding of health issues. MASSTART is a project that can help families with these and similar issues.

MASSTART is a joint effort of the Department of Public Health and Project School Care at Children's Hospital. Staff act as a link between family and school, to assist in development of the child's health care plan, train school personnel, and provide information, referral, and resources. Parents are always included in the process.

For further information or to make a referral, please call:

Boston Region:	
Betty Ficken-Bowen	(617) 727-0747
Southeast Region:	
Susan Larson	(508) 947-1231
Margaret O'Toole	(508) 947-1231
Northeast Region:	
Joan Daley	(508) 851-7261
Central Region:	
Margaret Harding	(508) 792-7880
Joanna McCarron	(508) 792-7880
Western Region:	
Julie McGee	(413) 586-7525

If you are not sure which region you are in, please call MassCARE at (617) 727-6941

If you are HIV positive and need dental care, the HIV ombudsperson program can help. Call (617) 534-4717

RIVER VALLEY COUNSELING

River Valley Counseling Center is located in Holyoke, MA. Its' HIV services provide: housing assistance; adult and pediatric case management; pediatric play group; mental health services and substance abuse counseling; outreach. advocacy, and transportation for people infected with and/or affected by HIV.

Child care and respite services, home health care, and legal services are also available.

Volunteer opportunities include participation on a consumer advisory subcommittee, fundraising, and support for HIV infected persons.

For information, please call 1 800-286-8221.

Submitted by Francine S. Lopomo, Program Director

Parents' and Childrens' Services
Homemaker Service Program

This program provides direct in-home help to families within the greater Boston area. A professionally supervised, expereinced, and caring homemaker is available to assist parents and individuals who are in crisis or who need on-going help. Services include: child care, cleaning, laundering, shopping, meal preparation, errands, and emotional support. Please call, (617) 437-1777.

CHILDREN'S AIDS PROGRAM OPENS NEW FACILITY

CAP [Children's AIDS Program] in Boston, a comprehensive respite program that provides residential and day care services to children with HIV infection and their families, has a new home! It has moved to a new building on the grounds of Boston Specialty and Rehabilitation Hospital in Mattapan. The Boston interior design community donated their time to design and furnish the interior of the CAP house.

The new facility includes a day care program for 20 children, with an outdoor play space, and residential respite care for up to 5 children. The staff is skilled in addressing the medical, nutritional, and other specialized HIV related needs of children and families.Other services include counseling and advocacy, drop-in day care, and in-home respite services for parents/caregivers.

If you would like more information about CAP, please call (617) 534-2050.

How To Reach MassCARE

Brunilda Torres, MassCARE director, and Katie Bond, parent consultant, can be reached at:

(617) 727-6941
Department of Public Health,
150 Tremont St., 7th floor
Boston, MA 02111.

You can also get information through the MassCARE coordinator at your child's clinic.

MassCARE Coordinators

1). **Brockton**
Rosie Vasquez: (508) 586-3600

2). **Holyoke**
Steve Torres: (413) 784-5014

3). **Lawrence**
Terri Tellez: (508) 685-1770

4). **Lowell**
Luisa Read: (508) 937-6100

5). **New Bedford**
Louise Norko: (508) 992-6553

Additional Resources

National AIDS info hotline
1-800-342-AIDS
Spanish hotline
1-800-344-7432
Hearing impaired hotline
1-800-AIDS-TTY
Mass state hotline
1-800-235-2331
Mass anonymous test site info
(617) 727-6971
Child SSI benefits line
1-800-882-1435

About MassCARE

The first goal of MasCARE is to expand and extend the delivery of HIV specialty care to five targeted cities in Massachusetts: Lowell, Lawrence, New Bedford, Brockton, and Holyoke. Four Massachusetts hospitals that have pediatric HIV clinics--Children's Hospital, Boston City Hospital, University of Massachusetts Medical Center, and Baystate Medical Center--have joined forces with community health care centers in each of the five communities. A team of medical personnel from each health center is linked with a team from one of the hospitals to provide follow up care to children who are at risk for HIV or who are infected with the virus. By developing a statewide network of services and support for pediatric HIV/AIDS, MassCARE works to insure that children who are HIV positive or who have AIDS and their families receive family centered, community based, comprehensive, and coordinated care.

The second goal is to develop statewide parent-to-parent support networks. This newsletter is one aspect of that network. Parents are also involved in planning weekend retreats, attending conferences, and becoming active on decision-making committees of MassCARE. ***Children do not have to get their care at a MassCARE clinic in order for parents to be part of our project.***

Parents are needed
to attend MassCARE coordinating committee. It meets once a month in Worcester to discuss the program at each health center.
Stipend for time and travel.

WOULD YOU LIKE THE NEWSLETTER ? IT'S FREE TO PARENTS !!!

Yes, I wish to receive MassCARE News by mail.

I want to help with MassCARE. Please call me.

NAME _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

PHONE _____

Please return this form to: Katie Bond, MassCARE, Dept. of Public Health, 7th floor, 150 Tremont St, Boston, MA 02111.

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MassCARE NEWS

Vol.1 No.3 | A Newsletter By Parents, For Parents | April 1993

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WHAT ARE CLINICAL TRIALS ?

WHAT IS A TRIAL ? A clinical trial [also called study or protocol] is a test of a new drug or treatment in people. The goals are to find out if the treatment is safe and to find out if it works. Doctors try to follow a very strict set of rules in order to get reliable information from the trials.

WHAT IS THE ROLE OF TRIALS IN HIV DISEASE ? Right now there are only a few approved treatments for HIV. Because the disease is complicated, it is important that new treatments be made available. Any drug that might help must go through careful testing before it can be made widely available.

SHOULD MY CHILD ENTER A CLINICAL TRIAL ? There are several reasons to take part in a trial: the chance to receive a treatment before it is widely available; the chance to receive additional medical services at little or no cost; the satisfaction of contributing to what we know about HIV disease.

The biggest risk comes from what is not known about the treatment. There is no guarantee that it will be better than any other treatment or better than none at all. A drug that works for some people at one stage of disease may not work for all people. It also may have harmful side effects. There is a chance that a treatment may help for only a short time. The trial tries to answer these questions.

HOW CAN MY CHILD BE PROTECTED FROM THE RISKS ? Before a drug is given to people, it must first be studied in the test tube and in animals to look for side effects and begin to learn about the

continued on page 3

ONE FAMILY'S EXPERIENCE WITH A CLINICAL TRIAL

Michael, our son, was three years old when the doctors told us that he could enter a trial for a drug called Nevirapine. We talked with the clinic staff, and they told us the details of the trial. We then discussed the options between ourselves. We were scared about the possible side effects and wondered whether to risk them with Michael. We went back to the hospital with more questions. How long had this drug been tested in adults? Had children taken it? What are the known side effects, and what might be its' benefits? After much thought, we decided to enter him in the trial.

One issue that we wish had been included in the informed consent was the possible emotional effects it might have on him. We never imagined the impact that the visits to the doctor, blood drawing, and daily medicine would have on Michael, in addition to his living with HIV and facing the "normal" challenges of life itself. If we had been aware this might happen, we would have had a therapist work with him from the start.

Today, Michael is almost five. He is on Nevirapine/AZT combined therapy and, instead of monthly doctor's visits, he goes every three months. This gives us more time for ice skating and visits to Chucky Cheese! We also have a therapist who helps our family deal with the issues of living with HIV.

If you are thinking about entering your child in a clinical trial and would like to talk with us about our experience, please call us at (603) 772-0903.

Written by Anthony Green and Kenneth Ward, parents of Michael.

Dear Parents:

Many of our children have been asked to take part in clinical trials. I hope that this issue helps us learn more about trials. I think the articles offer us ways that we, as parents, can take active roles in our child's care. Sometimes it is hard to remember that we are experts on our child's illness and have every right to be included as partners with doctors, nurses, and social workers in that care.

Please also take a moment to read the poem on this page. It is written by an eleven-year old boy with HIV. The poem moves me deeply, and I think it will affect you, too. If your children have stories, poems, or pictures, please send them to MassCARE. This is our newsletter, and let's share our kids' talents!

I wish you well.

Katie Bond, Editor

It Came Out of Nowhere

It came out of nowhere.
It had no point.
You can not see it or even hear it.
It killed the king and assassinated the queen.
Suddenly I felt it on my back.
Then I felt a prick.
Then I felt kind of sick.
I thought it was a ghost or maybe a vampire.
It could be a bug or even a frog.
It came out of nowhere.
It had no point.

Written by an eleven-year old boy who has HIV disease.

MassCARE NEWS Staff::

Editor: ..... Katie Bond
MassCARE Director ..... Brunilda Torres

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A CHANCE TO BE HEARD:
Join A Community Advisory Board

We invite you to become active in a group that can have great impact on the care you and your child receives. This group is called the **Community Advisory Board [CAB]** of the **AIDS Clinical Trial Unit [ACTU]**.

As you probably know, there is a great deal of research to find effective treatments for HIV/AIDS. In order to benefit from these drug studies, you and/or your child must be in a clinical trial. Each hospital that has ACTU trials is **required** to have a CAB.

CABs are made up of HIV positive people, parents of HIV positive children, case managers and other community caregivers. We work with hospitals and researchers in order to make sure that clinical trials meet the needs of people who are living with HIV/AIDS. CABs discuss a wide range of issues, such as: reviewing upcoming trials; making sure informed consents are written in a way that is clear; encouraging translation of materials into languages other than English; and finding ways to increase the number of women and children who are in trials

The three pediatric CABs in Massachusetts meet at:

Baystate Medical Center
Springfield
Contact: Maripat Toye, RN
413-784-5399

University of Massachusetts
Worcester
Contact: Lois Howland
508-856-3947

Children's Hospital/Boston City Hospital
Boston
Contact: Ruthie Liberman
617-442-6764.

Please call one of these people or MassCARE for more information. CABs are a great way to have your voice heard!

Submitted by Ruthie Liberman, Maripat Toye, and Lois Howland

Trials
Continued from page one

proper dose. It is then offered to humans through clinical trials. Doctors try very hard to detect side effects before they become serious. It is important to ask your doctor about possible side effects of the drug and to notify him or her promptly if they occur.

Each hospital has a panel, called an Institutional Review Board [IRB] that must approve the trial before it may begin. A second panel reviews the results and has the power to stop the trial if the people in it are in danger of being harmed by the drug.

WHAT IS INFORMED CONSENT ? Before you agree to a trial, you will be told the purpose of the study, the drugs that will be used, the possible dangers and benefits of it, the number of clinic visits needed, and the tests that will be done. This must be done in the language that you speak. You may take the clinical trial information home and read it, if you wish. Ask as many questions about it as you need with clinic staff and take the time you need to discuss it with family members or other people with whom you feel comfortable before you make a decision.

WHAT ARE MY RIGHTS ? As a parent, it is your decision whether to let your child enter the trial, and you may leave the trial at any time. If you decide not to have your child enter the trial, or if you decide to leave the trial after it begins, he or she will have the right to the same medical care as any other child.

WHAT ARE MY RESPONSIBILITIES ? If your child enters a trial, you are agreeing to take part in research that must be run according to a set of rules that you must understand and agree to try and follow. The number of tests and restrictions may seem like a lot of trouble, but they are designed to protect your child against unknown side effects and to get reliable information.

WHAT HAPPENS WHEN THE TRIAL IS OVER ? If the results are favorable, some trials offer the drug for free until it is available for sale. Discuss with your child's doctor such questions as: what will happen if the trial is stopped early or my child is removed from the trial; if the drug has no effect on most people but seems to work for my child, can he or she still take the drug? Get the answers to these questions before the trial begins so the process is clear to you.

Compiled from American Foundation for AIDS Research "AIDS/HIV Clinical Trials Handbook" by Amy Scharples, RN, Clinical Nurse Specialist, U. Mass. Medical Center, with additions by Katie Bond, Editor

For More Information on Clinical Trials

AIDS Clinical Trials Information Service: ***1-800-TRIALS-A***

National AIDS Information Clearinghouse: ***1-800-458-5231***

Additional Resources

National AIDS info hotline:
1-800-342-AIDS

Spanish hotline:
1-800-344-7432

Hearing impaired hotline:
1-800-AIDS-TTY

Mass. state hotline:
1-800-235-2331

Mass. anonymous test site info:
617-727-6971

Child SSI benefits line:
1-800-882-1435

If you have questions about MassCARE or would like to become active in our parent network, please call Brunilda Torres or Katie Bond at 617-727-6941.

Questions and Answers

Do you have a question about HIV or AIDS? Let us know, and we will have a doctor, nurse, social worker or other health care provider answer it in this space.

Question: What are the kinds of tests used to detect HIV in adults and children?

Answer: When an adult is identified as HIV positive it is usually on the basis of **antibody tests**. Antibodies are proteins in the blood that develop in reaction to the presence of the virus. The test is done in two parts on a sample of blood. Both types of antibody test, **the ELISA and Western Blot,** have to be positive for the test to be reported as positive. A positive test in someone over 15 months of age means the virus is present. It does not mean someone is sick with it or has AIDS. A baby born of a mother who has the virus will test positive for antibodies at birth. This is because his/her mother passes antibodies through her womb [uterus] to her baby. **In only 30% of cases, however, will she also pass the virus to her baby.** Therefore, for testing of children under 15 months of age, we need to use tests to look for the virus itself.

There are three major tests used to do this. The **HIV culture** is used to isolate the virus from white blood cells or whole blood. Detection of **p24 antigen**, pieces of the virus, may be another tool that is helpful in the first few months of life. A new technique, **ICD p24 antigen test**, can detect even smaller amounts of the virus. **PCR** is a powerful tool that can detect small numbers of viral genes in just a few infected cells. It has to be done under tight controls to avoid false positives.

New techniques are being developed to help us detect true HIV infection as early as possible. These allow us to offer medical care to children as soon as possible and to help us learn how the virus is passed from mother to baby. ß

This question from a parent was answered by Barbara W. Stechenberg, MD, Director of the Pediatric HIV Program at Baystate Medical Center in Springfield, MA

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I want to help with MassCARE. Call me.

NAME _____

ADDRESS_____

CITY_____**STATE**_____**ZIP**_____

PHONE _____

Please return this form to: Katie Bond, MassCARE, Dept. of Public Health, BFCH, OCSHCN, 150 Tremont St. 7th fl., Boston, MA 02111.